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# UCG Minor Internship Course UCG3RM01

BSc in Liberal Arts and Sciences, Health and Life Sciences

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**The beginning: deciding to do an internship, preparation and application.**

I had heard many times from my older brother, who studied biology, how important practicals are for the curriculum and professional development. Still, I did not fully realise this until the corona pandemic impacted education. When the pandemic first hit Western Europe, I was still a first-year student about to start my cool major courses in anatomy, physiology, microbiology, immunology, etc. However, from one day to the other, in situ education mostly disappeared and course practicals were cancelled or adopted an online nature. This situation prolonged throughout my whole second year of university. I soon realised how big of a gap my curriculum would have without practical experience, so I decided to explore the options of doing an internship in my third year of studies.

An idea that had been crossing my mind for a while was to pursue a Bachelor in Nursing upon graduation at UCG. Therefore, it seemed logical for me to choose a social internship instead of a research one and orient it in the direction of healthcare. The options were quite limited due to covid, and it was yet uncertain of whether or not, in the end, it would be possible to do an internship. Nevertheless, I began preparing for it in the first semester of my second year at UCG. My idea was to base it on the Care Internship curriculum from the BSc Medicine, but the critical question was, where could I apply? I would have loved to be an intern at the UMCG. Still, with little or non-working experience on my back and how complicated the situation was with increasing hospitalisations every week, it did not appear to me as a good idea.

The options I had left were nursing homes or similar institutions such as those for disabled people or mental health organisations. Luckily, I knew about an institution of intellectually disabled people close to Groningen because my dad had an old childhood friend working there. I talked to Sonia Mascarell , the internship coordinator at UCG, and asked her whether this would be an option and how I could organise it to meet the university requirements since Nursing in the Netherlands is not university-level education.

She encouraged me to apply for an internship position there, and so I did. First, I got better acquainted with the organisation by reading the information on their website in detail. I found this very important to show that I was aware of their history and philosophy. Then, I emailed the internship coordinator office and sent them my motivation and CV. They usually welcome interns from studies such as social work, nursing, pedagogy and medicine. But I was an unusual intern! They must have liked the idea, so they invited me for an interview. They wanted to hear more about my background during the interview, and they found the multidisciplinarity at UCG very attractive. We also discussed working hours and my options within their institution to fulfil my learning goals both professionally and personally.

Shortly after the interview, I received an email with their decision of accepting me as an intern, and, of course, I was thrilled! From then on, everything went quite smoothly. There was still some paperwork to do from the side of UCG, such as finalising my learning plan and submitting it and signing the contracts. Additionally, there were some formalities from the institution's side: I had to receive a Certificate of Conduct from the government to prove that I am a good citizen and wouldn't cause any damage to the residents of their institution. I had to sign a document for professional confidentiality stating that I would not disclose sensitive information. And, the money-related part... I had to sign a document giving my bank account details and stating whether I had a side job for them to transfer me the internship compensation to cover transport costs and, in general, to repay me for the services provided to the institution as an intern. This was not a salary, but merely a small compensation of 355€/month. However, since in my home country (Spain) I had never heard of interns getting *paid*, I most definitely was positively surprised.

Finally, everything was in order, and I could not believe that I was about to start a three-month internship within a Dutch healthcare organisation. Especially because Dutch is not my mother language and even though I had been studying it for a while because I need it for my further studies, I am not entirely fluent at it yet, and I knew that it would mean an extra challenge for me in the context of my internship. I felt a mixture between excitement and concern. Nonetheless, I was looking forward to the start.

**Expectations prior to the internship.**

When something new is about to happen, it is normal to be nervous and have certain expectations. For me, something that I could not help wondering about was how I was going to manage to do a full time demanding *job* with my poor Dutch. As silly as it may sound, this took quite some of my energy and my expectations were unconsciously mainly focused on it. What would my colleagues think of it, would I manage, would the internship help me improve my language skills, etc. Of course, I also wondered what my colleagues would be like, whether it would be a pleasant working atmosphere and all those basic questions. Still, I honestly expected a welcoming and warm environment from the interview moment.

Moreover, I expected to have my general internship supervisors as the main point of reference and regular meetings with them. I also awaited to learn a lot about the healthcare working environment and the daily handling of patients. I hoped to learn a lot about myself personally but as a potential future healthcare professional too. To find me in a healthcare environment and how I function in it. Would it be doable, exhausting, would I be able to meet the expectations that others would have on me, would I be able to apply previous knowledge and give my insight into certain circumstances?

Lastly, I expected to have more free time thanas a regular student. Yes, this was an important expectation that I had. As a student, you are constantly with your studies in your head, especially during corona when there was not much else going on, and I expected to have some free time after work. However, this was not quite the case, as described later in this report.

**Nieuw Woelwijck.**

Nieuw Woelwijck is a village community of intellectually disabled people. While mentally disabled people shared space with psychiatric patients in the past, there were soon initiatives to create a permanent living environment for the first. Here, they wouldn't be treated as patients but as residents actively part of a community. This is the main idea of Nieuw Woelwijck. It is an organisation where residents are given the space, time and guidance for personal growth beyond their condition and to carry out a life as 'normal' as possible within the adapted and safe environment provided by the village. Given its permanent character, Nieuw Woelwijck is meant to become a home for these people. The village is located in a nature area, and it is divided into two neighbourhoods with houses where residents are grouped based on their intellectual level and disability. In the centre of the village, the reception, administration, doctor's house, pharmacy, remedial educationalist office, physiotherapy are located. Other buildings on the main square are the grocery store, clothing store, the grand cafe and the workhouse. It is almost like an authentic village!

More information about the institution can be found in their website (https://nieuwwoelwijck.nl/) but I also recommend the following document:

https://nieuwwoelwijck.nl/wp-content/uploads/2011/11/nw-missie-visie-en-praktijk-internet.pdf

**My role at this organisation and reflection.**

During my time at Nieuw Woelwijck, I have had the honour to work hand in hand with a wonderful group of people taking part in the daily care of residents with severe to profound intellectual disabilities. Within this group, I received guidance and feedback to carry out the job tasks as best as possible and learned not only from the other employees but also from the residents themselves. I have also had the chance to learn how the institution works and take part in sessions given by the remedial educationalist. Moreover, I researched a relevant topic for the field of intellectual disabilities and the institution.

To address this section of my report, I will divide it into two parts, describing the tasks given by the institution based on the goals from my learning plan:

1. Professional learning skills:
    a. Tasks carried out in the house that I was assigned to.
    b. University level tasks.
2. Generic learning goals.

In addition, I will reflect upon these three big groups of goals below each section. This, in my opinion, will give the report a neater format.

1. Professional learning skills.

a. Tasks I carried out in the house that I was assigned to include:

- Physical daily care and hygiene of residents: washing, dressing, eating, drinking, ensuring the cleanliness of the residents and their environment.

I started on a one-to-one basis, caring for one resident at a time. Throughout the internship, I was given more responsibilities by caring for small groups with and without supervision. I have learned basic caring skills such as washing the residents skilfully and respectfully and administering food and drinks. Also, bringing residents to bed with helping tools such as patient lifts and slide sheets and placing them in a favourable posture (left, right or facing up) with the help of plastic supporters as described by the instruction manuals provided by the physiotherapists and medical doctors. I was also expected to provide assistance with excretion (micturition and defecation) to those residents that needed it by, for instance, administering laxatives (*movicolon*, *microlax*...).

- Observing/assisting wound and stoma care and other treatments or procedures.

This includes tasks more related to nursing skills, such as applying ointments (e.g. eczema creams, antifungal creams) on skin lesions, infections or irritation resulting from stressors producing skin irritation, self-mutilation or (fungal) infections. I also had the chance to observe the nursing team changing a PEG-probe, and I was frequently asked to care for the gastrocolocutaneous fistula of a resident during physical care moments: cleansing, rotation, protection by cotton covers and reporting status. Moreover, I attended medical and dental consults (diagnosis and treatment) and procedures such as blood extraction and injections. I also had the chance to observe the performance of the Heimlich manoeuvre by the medical team to a resident that had unfortunately choked on their food.
Lastly, I attended a short informal introduction to injections relevant to our residents in the doll-room, where I had the opportunity to practise injection methods, such as intramuscular and subcutaneous.

- Help with medication administration.

I was not allowed to administer medication with medical prescription independently, but I did administer laxatives (movicolon, microlax) and vitamin supplements to residents that needed it.
I was allowed to provide a double signature in the medication control file (a double-check) for dangerous liquid medication that needs to be prepared every day at the correct dose (liquid Depakine, as a treatment for epilepsy). In this case, either I prepared the dosage myself with supervision, and a supervisor checked that it was correct, or I checked the proper preparation of the medication by a healthcare worker and gave an approving signature.

- Skilful, respectful, and careful handling of patients during basic nursing procedures.

Taking time to carry out procedures not to scare or disturb the resident. Use soothing techniques such as using calm, easy talk or slow singing. Use tools to make transportation easier and cause the least physical discomfort and disturbance possible.
Promote privacy practices by closing doors or placing folding screens during handlings in the bathroom or when residents are (partially) naked.

- Case management: daily control of the patient's condition and health promotion.

Every day upon my arrival, I needed to (when possible time-wise) read the reports made by workers from previous shifts about each resident. In the report, there were certain things included: particularities (special days, events), physical well-being (which factors played a role in the state of the resident, consequences of epileptic seizures, medication incidents), psychological well-being (was there tension or relaxation, which factors played a role in disturbances, difficult moments, the perceived mood of the resident), visits or phone contact, appointments with healthcare professionals or other kinds, and reporting on the goals of the care plan.
At the beginning of my internship, I was asked to report to supervisors about the residents under my care verbally. Later, I was on certain occasions expected to report on paper about the residents that were under my care for other workers to read.
I also took part in team meetings and gave my perspective of the residents' condition and how I think it could be improved.

- Communication in healthcare: Observe the patient's emotional/physical needs and answer appropriately. Understanding the patient's level of dependency through verbal or non-verbal communication and to what extent are they aware of their situation. Communicate respectfully and empathically with the residents, their families, and other staff members.

I was able to emphatically and respectfully talk to parents or legal representatives, serving as a communication bridge between their sons/daughters and them and reporting to them the status of their children with tact, honesty and warm treatment. However, this was also limited by my language skills and position as an intern.
Part of the job also involved talking to coworkers about the different handlings of the residents, deciding together what and how is best to carry these out in the circumstances of each day. Talking to the residents with care and consideration even when they are unaware of what is happening. Without overlooking their awareness during procedures and activity moments.
I also reported clearly and precisely about the state of the residents both verbally and on paper.

Reflection about the tasks carried out in the house:

I had no idea what was ahead of me when I signed up for this internship. This should not sound scary, as it was not, but should serve as a reflection about how the practical side of a job is an entirely different story than what it sounds like on a first instance on paper. Nevertheless, I am delighted that I was given this fantastic opportunity. As described in the other reflective parts of this section, it was a lot of work and, to be completely honest, a lot of tears too, but also a lot of smiles and positive surprises.

About the part of my learning plan described above, I can proudly say that I have learned a lot about physical handling procedures and basic nursing skills (professional skills). In healthcare, there is constant improvement, and you can never master the skills 100%, but I became reasonably competent as an intern. In the beginning, I was closely supervised in the tasks carried out. Slowly I noticed that they were giving me more space, and if I wanted something to be double-checked because I was unsure whether I did it correctly, I had to ask someone for help explicitly. In this field, it is not only a matter of whether I was able to do something in general, such as bringing someone to bed and laying them properly with the supporters, but a matter of who I was bringing to bed, since each person is different, their body is different, and they have different needs. This actually applies to any handling and complicates the learning process.
While at the beginning I felt so bombarded with stimuli that I was barely able to clearly and calmly look at the residents individually, when I became more used to the environment, I soon realised that my main focus should be getting to know these people I was caring for. Who are they, what do they need, what do they like, what do they not like, what works better for them, etc. At the start of my internship, I could not see much in them due to their heavy limitations and disabilities, but if you take the time, even if it is just asking yourself these questions, you begin to see how each of them has their own story and their role in life, their function with others, and not only what role or responsibilities you have for them.

This did not only humanise the care I was providing them with but also improved the way I cared for them in all tasks mentioned above. I sometimes even asked my colleagues to observe for one shift or specific moments. I realised that the eagerness I had to *do* and *learn by doing* at the start of my internship was balancing with the importance of observing in order to *do* better. My reports were more accurate, and I was able to notice more things in their behaviour and both physical and mental wellness.
I got more in-depth into this matter during my research and article development, which also helped me carry out my tasks better. My colleagues and supervisors noticed the change, and their feedback improved over time. They also encouraged me to take on more challenging tasks, and even though at the beginning I was doubtful, I followed the advice, and I am glad that I did, for I was able to expand my limits, apply my previous knowledge in specific scenarios and become more confident in my role.

b. University level tasks: Literature-based research on the topic of non-verbal communication supervised by the remedial educationalist (*orthopedagoog*) of the institution. (See appendix 1. Note that the final version of the article was in Dutch.)

Investigating what a care plan is, developing a care plan based on a case study found online and receiving feedback from it from the remedial educationalist of the institution since she is the one in charge of checking the care plans designed for every resident. (See appendix 2, note: it was written in Dutch and does not contain feedback as this was given verbally).
I also took part in the *Ontdekkend Kijken* (Discovering awareness) sessions designed by the remedial educationalist to study and assess a resident from closer without all the other stimuli and try to see new things such as movements, facial expressions, and body language that was not discernible or regarded as less important before (See appendix 3).

Reflection about the university level tasks carried out:
-Research: This was my little Everest from the internship. Though I presented my topic choice and my supervisors liked it and looked forward to the result with interest, I had to structure the whole thing myself. It felt a little bit like preparation for my bachelor thesis, which is good. Yet, I felt at times lost in the articles I was consulting and worried about how I was going to put the information researched into a coherent and, most importantly, relevant piece of text. I found myself being stressed about it after work when all I wanted to do was rest from the intense working hours. This was mainly at the beginning when the research was still acquiring shape, and I was figuring out a more concrete structure. But once I had a clear overview of what I wanted to talk about in each section, the article almost wrote itself, which gave me a lot of peace of mind, and I was able to finish it well on time. I submitted it hoping that they would find it pertinent to the field and somewhat of inspiration for their practices. It also helped me better understand the importance of institutions like Nieuw Woelwijck and, more importantly, humanise the daily treatment and handling that I gave to my group of residents.
Something else that I would like to reflect upon here is that I didn't expect the research to become such a big part of my university tasks. Due to the holidays from my supervisors and that I had to account for so many people, it became a little bit chaotic to plan other tasks, for instance, from the policymaking or public health departments. That is why what should have been a relatively short article turned out to have so much weight. It basically became my main (and arguably only) actual university task, and it required one less working day at the house to provide me with enough time to carry out the research. I adapted pretty well to the new circumstances and took it as an opportunity to prepare myself for the bachelor thesis, which I also intend to do based on a literature search. I was also glad to have a day to work from home, on my own terms, and I consider that I made good use of this time employing little deadlines that I gave myself and submission on time and without last-minute stress. Therefore, I can say that I am pleased with the time management and organisational skills that I have shown here.
Furthermore, I wrote the research in English but had to submit it in Dutch. I did my best to come up with a good translation, but I also asked help from my partner and my father, both Dutch and who were happy to help me and make the final language adjustments.

-Care plan: This was not necessarily a university-level task if it had not been for the research behind it and the feedback conversation held with the remedial educationalist of the institution. I included this task in my learning plan because I thought it would be an excellent way to investigate the importance of care plans, by who they are developed, on the basis of what, and to see real-life cases, thus care plan and resident together. I created

the care plan based on a case study found on the internet. I was eager to do a good and complete one, and so I did. However, throughout the conversation with the remedial educationalist, she explained how even though she found it very comprehensive and accurate, at Nieuw Woelwijck care plans are usually more straightforward. They are supposed to last a year maximum, and they mainly approach one single goal, achieved if at all step by step. Though it may sound quite evident as I described it, I had been utterly oblivious to this simple principle. I found this conversation with her interesting and agreed with her feedback. I realised once more that sometimes things are made too complicated on paper, and though correct, they might not have a real-world direct application. Why is this relevant to me as a UCG student and a future applied sciences student? Easy. As a problem solving, project-based education, it is important to realise the line between theory and practice. Sometimes, it is essential to explore the field before making plans and policies that may be too intricate and elaborate to be applied.

-Ontdekkend Kijken/Discovery awareness method: As an "outsider" I found it interesting not only to observe the video of the residents but especially the reactions given by the team of workers. I participated too and presented my views, but after writing my article, where I address methods of observation similar to this one, observing the dynamics of the meeting and the responses and impact these had on others became more interesting to me. I felt both like a co-worker taking part in the process and at times as a scientist carrying out observation research, observing my co-workers behaviour in this natural situation without interfering.
This activity was especially organised so that I could attend, since it usually takes place later in the year. We thought it would be useful to give everyone some hands-on experience in the context of my article's topic that they would all be able to read later on. On the other hand, one of the feedback points obtained for my article was that they would have liked it if the Discovery Awareness method would have been included in my paper. Indeed, I think it would have been a great idea, but unfortunately I did not realise this earlier.

2. General learning goals: For this section, instead of describing each point, I will focus the description directly on the reflection.

- Professionalism: handling the patient's physical and mental care professionally. Learn to deal with my feelings/troubles regarding the high demanding healthcare working atmosphere. Resilience constitutes one of the fundamental abilities to develop throughout this internship.
- Communication: effective professional communication, in this case with other members of the staff, residents and their families. Be able to communicate clearly and effectively about my role (as an intern) and reflect upon my tasks and professional development. Communication within the research.
- Collaboration and co-organization: application of communication skills when building professional relationships with residents and co-workers. Giving new ideas and my perspective, providing feedback on other people's opinions and comments.
- Personal development, skills and attributes:
    - Assertiveness: communicate or act honestly, being able to show my point of view or defend my own boundaries while still promoting a positive

atmosphere, being respectful to others and taking their perspectives into account.
    - Punctuality as part of showing responsibility and dedication to the job and promoting a good working atmosphere and building trustworthy relationships with co-workers and residents.
    - Thinking creatively and resourcefully.
    - Enhance patience. Not all problems can be immediately solved. Building relationships with both co-workers and residents will take time.
    - Promote a good atmosphere within my team and the group of patients assigned to.
- Time management skills: provide qualitative and quantitative good work also under some time or task pressure. Flexibility and adaptability.
- Realize the difference between the responsibilities a student has for themselves and occasionally group members, and the high-demanding responsibilities of working ( in healthcare) and behave accordingly.

Reflection about general learning goals:

The first couple of weeks of the internship were incredibly tough. To start with, I had to get used to waking up early. And when I say early I do not mean 7.30am. No. I mean 5.30am. Basically, every day, unless I had an evening shift or I had free. Then I would need to bike, take a train and again bike to get to my destination, which at such an early time seemed like a whole Odyssey just before an eight hour shift and then, the way back. I reflect on this because I believe that the internship is constituted by the whole experience during those three months and not exclusively the working hours. An upside of the whole train adventure is that I was on time every single day (punctuality), except once when there was a problem with the trains, but that was out of my hands. As I explained above, I think that punctuality shows responsibility and facilitates a good working atmosphere. It also enhances the level at which co-workers are willing to rely on you. So looking back at the internship, I would say that this went pretty well.

During the working hours themselves, there was an incredible amount of new input: lots of noise caused by the residents themselves, part of non-verbal communication, automatic behaviour, pain etc, plus what had to be done across the different shifts. At the beginning, I tried to hold on to every piece of information, which was not a good idea energy-wise. I would arrive home completely devastated and some days even with tears in my eyes out of pure exhaustion. On a few occasions, it became too heavy for me during the working hours and I had to ask to leave the site for my own good and also with the residents in mind, since it is not alright nor professional if you are emotionally not fit to work and the residents see you crying or struggling during their care. At the time, I talked about it with my supervisors and they said that it is not something that I had to feel ashamed about. It is after all a learning process and we are all humans and therefore not made of iron nor expected to be. They found it important that I was able to notify about my boundaries and in a professional manner (assertiveness). However, I did find it difficult to do so. BeforeI had this conversation, I was actually quite scared that they would think of me as unfit for the job and that they would ask me to stop the internship. Then I realised that it is okay to acknowledge your own vulnerability and that it does not make you weak as long as you are

able to reflect on it and learn from yourself (resilience). Slowly, I learned to manage my emotions and my time and energy more efficiently. I still found it tough at times but I got somewhat used to the habits of the job and this gave me a lot more mental space to actually start learning about it, seeing the little things and maybe most importantly enjoying myself.

After this conversation and after talking to my academic supervisor, I realised that it was really important for me to communicate clearly to my colleagues about my role as an intern. Especially because it was the first time that they had an intern like me and my main supervisors did not work in the house that I was assigned to, but were instead in the administration building. At the house, they were generally used to interns with very specific learning goals from studies like nursing, or social work where you need to be capable of entirely performing the job by the end of their internship. For them, internships last for a minimum of half a year, but I was only there for three months and had other requirements. I feel that at first my role as an intern was at first quite unclear and that co-workers went along with it, happy to have me on board but without fully understanding what to expect from me, so it was important that I was open to them about my role and responsibilities as discussed in the contract. After clarifying this issue, I was able to bring new ideas and take more initiative when problems arose (thinking creatively and resourcefully), and to promote a better atmosphere within the team. It also became easier for them to understand what could be asked and expected from me. From that moment on they could see better my potential and were more open to my perspective as an outsider, valuing my academic background, which also made me feel more comfortable in my position.

Something that I would like to reflect on that I did not entirely achieve was working under time pressure in the context of the house tasks. I worked mostly on a one-to-one basis on activities such as physical daily care and in comparison to experienced colleagues I carried these out relatively slowly. They said there was no problem, since it was beneficial to have someone that was able to take their time with each resident, but that in the actual job sometimes you need to be a bit more effective and make choices to carry out some handlings quicker since otherwise you are not able to attend everybody. They did see an improvement across time, and I saw it too. I was able to be more functional in moments that required so, but remaining attentive and thoughtful when there was more time.

Another important learning goal that I had was “enhance patience”. This was a goal present in my head every single day of my internship. Why? Well, when you work with people who are not able to live in any time but the present, you need to slow down considerably. We now live in a society where with all the technological advances we are used to having many things solved immediately. We barely have to wait for anything on a daily basis and are often occupied with things that are yet to come. But during this internship, with this group of people, nothing exists but the present. Of course you have to think ahead on procedures or appointments, but I was mostly forced to be right here right now. I am extremely grateful to the residents for this present. With corona, I have been looking too much into the future and they taught me how important it is to slow down and be aware of the moment. I believe that if preserved, it will help me in every circumstance in life and as a student it has its advantages too. Taking a deep breath and tackling things one by one, with a future perspective but without running, reduces stress greatly, something that I have been struggling with for the last couple of years.

In regards to my language skills, I am really happy with the improvement that I have experienced across the internship. While at the beginning I was shyer and maybe participated less in group discussions because these were quite fast and language-wise advanced, I soon let go of the fear of making mistakes and just tried to take part in them. I found that people were happy to listen to what I had to say and in the case that there was really no time for talking they would tell me directly. At first, this came across a bit too direct, but this was mainly a cultural difference that I needed to get used to and in the end, I was actually grateful for it.

Finally, I have to say that getting used to a full-time working environment was tougher than I thought. It is a completely different dynamic to be a healthcare worker that, as a student, to make sure that my group meets the deadlines successfully and that we submit a good piece of work or get my assignments done and study for my exams individually.
Furthermore, within the nursing sector, where your job requires intensive caring for others with disease or in need, there is a higher emotional demand that one needs to learn to cope with. I believe this is a long process and that even the most experienced workers are still working on it every day.
If I look back at myself prior to the internship, even though I was aware of the pressure and exhaustion related to healthcare jobs since several family members are in the field, I dare to say that people who have not experienced it first hand can never really know how hard and emotionally consuming it is. However, they also probably cannot quite imagine how gratifying it is to help others when they are in such a vulnerable physical and mental state. I myself have only had a first bite in it and have hopefully a long way to go. There is plenty that I have not realised and experienced yet, but I sure am looking forward to it.

To conclude this section, one of the things that I find most essential for anyone that wants to work in this field, is to get to know yourself, your limitations, your vulnerability, your strengths, your hopes, and approach those who need you with professionality but also with your most humane and compassionate side. Something that a nurse at my internship used to say and that I find very beautiful and wise is: “We are all people after all”.

**How to manage your expectations/ Expectations vs. reality**

Even though I have already regarded some of my expectations in the reflective sections of this report, I will focus one section specifically on them and will address them concisely one by one. Before I begin, I would like to remark that the expectations you have during the internship do not only consist of those that you have prior to the internship but rather appear throughout the course of the placement. In the beginning, one has rather a small part of the big picture in the head and this becomes more complete upon the start. I will begin by addressing those expectations that I had prior to the internship and then I will add some of those that appeared throughout its course.

-Dutch language: I look back at this and I feel quite proud of myself. With all my insecurities regarding the language, and being rather anxious about social situations in Dutch, I jumped fully into this situation and did my best. Even though at times I felt like *what am I doing here*, and believe me there were plenty, I kept trying and being perseverant. It is very difficult to realise how difficult it is to learn a language that you speak rather fluently since you are able to remember. So I was scared that people would become impatient with me or that I would not be able to keep up and make myself clear. However, I chose the wrong people to have these expectations with, since nurses and caregivers need to be patient by

profession. Everything went really above expectations. I learned a lot of professional terminologies and I found everyone being patient and valuing my efforts.

-Supervisors: In this regard, I had a mixed experience. On the one hand, all of them were very attentive and willing to help me but on the other hand, I had a supervisor for each thing: one in the house, one for the university tasks and the two main ones. This became rather stressful for me since I had to notify all of them of my progress but I also had to account for all of them: when were they free, what was possible, when was it possible, etc.

-How I function in a healthcare environment: I think that I expected to find myself like fish in the water since I grew up with close family members with a profession in healthcare. However, it was more complicated to adapt than I expected. I mainly attribute it to the language's challenge to the already stressful working environment. I did not only need to learn to cope with the latter but to do so in Dutch. This made me realise how hard I will need to work throughout this academic year in order to reduce problems when I begin my nursing studies next year. In addition, it is not the same to imagine something that to actually do it and I tend to have high expectations since I am a perfectionist. This internship has also helped me to leave that a bit behind and rediscover myself from the perspective of these new circumstances. The truth is that in healthcare you are constantly learning and will never be able to do things 100% as you wish. Many things are out of your hands and if you are a perfectionist you need to learn to use that in your favour and within your job limitations, otherwise it can become frustrating and disadvantageous for yourself. I realised this shortly after the start.

-Previous knowledge: Previous knowledge from my major was very helpful in the house because it gave me insight into things that otherwise would cost too much attempts or time. My brain worked quicker with the clinical information received from a resident and I was able to react quickly in circumstances in which maybe otherwise I would not have known what to do. However, most of my previous knowledge until now was more on the molecular level, parts of the human body and processes, so I was quite new to dealing with actual patients/people. It did help with the research task. Not specifically knowledge from my major but in general academic and research skills.

-More free time: This was an unreasonable expectation. I had no idea how tired I would be. However, across the weeks of the internship and past the initial unbelievably days, I learned to cope with this and when I did have free time I took the time to take care of myself and I believe that I enjoyed the little things like reading, singing in the choir, doing something nice with my partner or meeting a friend more than when I had all the study stress in mind. This was part of the *being in the present* effect and was very gratifying.

-Train ride: The first two weeks of the internship waking up so early in the morning, biking and taking a train was not really an issue. Everything was new, I was excited and I managed to go to bed early. Plus, the village is in a beautiful nature area and I could not believe I got to *go to a forest* every day. However, when that excitement passes, getting up so early though a habit becomes tougher. When September came I started to have committee meetings, choir rehearsals, yoga classes, this nice movie I wanted to finish watching, friends, etc, but I still had to wake up at 5.30-6 am the next morning, or sometimes I had an evening or a weekend shift. Less sleep, an unbalanced schedule and the same working effort was definitely not a good combination.

-Public health and policy-making tasks: In theory, my university-level tasks were going to be quite varied. However, I had to arrange it with the supervisors and other professionals at Nieuw Woelwijck in these departments upon the start of my internship because I was told that it was complicated to arrange it beforehand. Something that I did not count on was the

workers holidays, the irregular working shifts and having to account for so many people. In the end, these tasks were not arranged. Therefore, my expectations in this regard were not met. Although I felt sorry since I thought it would have been really interesting for me, we managed to find a nice alternative that was my broader literature research-based article.

**Summary of the feedback obtained.**

During an internship like this one, it is normal to receive feedback mostly verbally along its course. As previously mentioned I had several supervisors for the different tasks and had to find moments to talk to all of them. In general, they were very happy with me and to hear this gave me confidence and motivation to improve those things that could be improved. I will summarise the feedback obtained in three sections: feedback at the house, university tasks feedback and final assessment.

-At the house: I formally received feedback from the person in charge of the interns' supervision. We would find a moment across the day to sit down and talk about my learning goals, or about my experience so far. Given that we took the time from the shift itself, since there was no other moment to meet, the meetings were not long because we had residents to attend. Therefore, the first times were more to get to know each other and for me to explain to her a little bit the overall picture of my internship and the requirements. In the beginning, she told me that they were very pleased with my work and that they found it interesting to see someone from another background (both academic and culturally) carry out the tasks that for them are so natural after so many months/years. At a later stage of the internship, she became increasingly comfortable with me to talk frankly and said that I was doing very well for the little time that I had been there but that they as a team thought that it would also be nice to see me perform full parts of a specific shift, increasing progressively my responsibility, and to take more initiative with some of the things that on the first instance I found scary to do. I received ongoing verbal feedback about the procedures, care, and handlings themselves from the workers that I had a shift with on different days. For instance, whether I was curing a wound properly, how to better use the helping tools to bring residents to bed, if one of the residents had an epileptic attack, what I was doing wrong and how it could be improved, in cases with autism that you need to do things on a specific order they corrected my actions or told me to choose moments to disrupt the order to help the flexibility of the resident, etc. Sometimes, I asked for feedback myself. Especially in situations where I thought a double check would be appropriate or make me feel more assured that I did things properly. For example, whether the way that I laid residents in bed was good since every resident has their own body shape and it is not enough to learn how to do something but you have to apply it to every case, or whether my daily report was complete enough or if I was missing something important.
I received written feedback only at the midterm evaluation, on the UCG midterm evaluation form. The interns' supervisor at the house said that she understood that it was a protocol from the university for all the different internships but that for me the best feedback was the one obtained from the co-workers on a daily basis. She also remarked that the grade given for the midterm evaluation was lower than the one they were foreseeing for the end since I had not yet submitted the article and care plan (planned for the second half of the internship) and because of their experience it is nice to have an improving process showing in the grades, taking more tasks and responsibility, rather than from the start receiving a high score on the basis of the tasks carried out until then. I found this completely understanding and definitely applicable to the context of the internship.
In general, I have to say that I learned a lot from the co-workers but also the residents, who give *feedback* in their own ways. For instance, sometimes I would be awaiting feedback from a colleague when all I had to do was listen/observe better the reactions from the residents. I learned this with time, of course, no one comes to a new job with no experience and does

everything perfectly fine from the start. In short, I am happy with the feedback obtained and the way it was given and I do believe that everything I learned across this internship will most definitely have a positive influence on my future nursing career and upcoming internship from those studies.

-University tasks feedback: This was a one-time thing. And with this, I mean that there was no supervision along the way but just at the end, upon submitting my article and my care plan, I had a talk with the remedial educationalist to hear what her thoughts were about my submissions. She was generally impressed with the article and observed openly that she found it of great interest. She said that the structure was good, a nice flow from the theoretical basis or historical origin on the topic to more real-life applications. The only thing that she did criticise was that the type of observing method that we carried out in her sessions (Ontdekkend Kijken) was not included in the article and that she found it a pity, but that for the rest it was a well-written paper relevant to their field of work and their institution. In this regard, all the feedback received was quite positive and I was very pleased to hear so.
I would have liked more support and maybe a pre-submission deadline with some feedback so that I could improve certain things for the final version. However, I think that the way it was organized had its upsides too, for instance, that I had complete freedom with the topic development.
For the care plan, I did receive more review, since I developed quite a complicated care plan and she noted that care plans should be concise, relatively easy to implement and more focused on a single goal. She explained to me that at Nieuw Woelwijck care plans are meant to last a year maximum and therefore should not be too intricate. This made lots of sense to me and accepted the feedback with an open mind and a positive attitude, already taking notes for my future career.

-Final assessment: I had a final talk with all three supervisors, the one at the house, the remedial educationalist and with one of the main supervisors. They all showed themselves content and satisfied with the work done and were sorry that my internship was over. They did tell me in general lines what they had filled in for the final assessment since they thought it was important for me to know what was told about me at the university. When they said this, I thought that bad news were about to be told, but this was just my nerves since everything seemed positive and in order. They did notify me that the assessment was filled in by all three supervisors, each completing what each of them attained. Further, I expect to hear the final evaluation from my academic supervisor any time soon after the submission of my report.

**General tips for future students.**

For this section I will provide some bullet points that I think would have served me of help at the start of my internship:

- It is really important to read from the beginning the course guide and learn what preparations and formalities are needed. Then you will have no last-minute bad surprises!
- Keep an open attitude, what at the beginning might seem bad or terrible or you might even wonder what you are doing there, can change completely across the course of the internship and those things that you didn't initially understand may brighten up or you may learn to focus on details that give sense to the overall image. Perseverance!
- There is nothing wrong with asking for space or recognizing and setting your own boundaries. In order to learn you have to determine how much you can learn or do

at a time, in a job like caregiving it can get really overwhelming and there is really nothing wrong with saying "I need space, I will observe, I need to take a break, I need to start with something easier. You are not supposed to be able to face the toughest of circumstances all at once, you learn best when you take little steps, and you will find that things that you found really challenging at first become more doable and easier and you will be able to understand them and yourself better.

- You might be doing things good enough and not obtain feedback on those things, but in healthcare, you can never do things 100% perfect and you can always improve (it is a lifelong learning process after all). Of course, you will obtain feedback when you do things terribly (which hopefully will not happen) but what is for sure is that in order to know how well you are doing and how happy your colleagues are, you will mainly need to ask for this feedback yourself. Never stop learning!
- Take time for yourself to do fun things, it is not okay if you bring home the troubles of work and vice versa. If you are tired, better than laying on the couch, going out and meeting with people, even if you don't really feel like it, it will certainly do you good to have some variety in your routine. Of course, it is also important to listen to your body but sometimes *being tired* also becomes a habit and it is a difficult one to leave behind. Don't put all the focus on your work, if you are overwhelmed or on the edge of burnout, there is also less information that you will be able to absorb and less energy to learn new things.
- To avoid unnecessary stress and energy loss choose when possible a location close to your house. Ideally, a bike ride away. This may sound silly but having to travel on top of doing such a demanding internship can become really exhausting. And if you do need to use a public transport service and you have the right to a student travel discount it is definitely worth it to set your OV-card on weekdays!
- And lastly and probably the best advice I can give you: Be prepared to learn from the most unexpected people and circumstances.

**Future career.**

To be completely honest, throughout the internship I have had contradictory feelings about my future plans. When I found myself in such an exhausted state I began to wonder whether I made the right choice regarding both the internship and my prospective studies. I could not help but wonder whether I should have followed the neuroscience minor in order to be able to apply to any Biomedical Sciences master program. However, it is important to put everything into perspective, and I realised several things that helped me do so.

Firstly, I was only getting used to a working routine that I had never ever experienced before, and this required time. Secondly, I am sure that I want to study nursing and any other thought seems now as an escape route when doubts arose or I was too tired, which I find natural and I believe everyone experiences conflicting feelings of this kind in stressful situations. Thirdly, this experience helped me to have a first-hand experience of a job in healthcare, but there are so many specialisations within nursing, I do not need to choose disabilities if I am not entirely convinced by it. And I have to say that no matter how nice the experience seems in retrospect, I found working with severe to profound mentally disabled people really emotionally challenging in a way that I had not expected at all and very physically demanding. Therefore, I certainly will not be choosing this specialisation in the future unless something changes drastically for me. However, I do consider that I made the correct choice by following this internship. I have not only learned a lot about the field, but mainly about myself, my body, my mind, my ideas and opinions, and my professional skills. I feel that I have undergone important personal growth and I will carry this

experience and what I have learned from it with me for the rest of my career and my life. Furthermore, I have also made new useful connections in the field and added them to my Linkedin profile which I think is important in order to support the practical experience that appears in my CV.

In regards to the start of my new studies, I will probably be at first *overqualified* to begin as a first-year bachelor of nursing. I have often received comments such as *why don't you do a master's, doesn't it feel like a step backwards*, etc. However, this is what I really want to do and to be *overqualified* does not necessarily have a bad connotation since it will hopefully open new doors and opportunities for me that otherwise I would have less access to or would cost me way more effort to do so (e.g. certain projects, *duaal* modality). I would like to clarify that when I say *overqualified* I am mainly referring to all the academic and soft skills that I have learned throughout the course of UCG in comparison to the level of admission to the bachelor of nursing and not necessarily to the content of the bachelor itself, though this might also overlap at times however from a more practical perspective. I am in fact very proud of these soft skills because I will already encounter difficulties regarding the language and these skills will most certainly make my life easier across the study. In addition, everything that I have learned during this internship will serve as a fantastic basis for the internships I will carry out as a nursing student, especially at the beginning of the studies when everything is new, and will also give me insight into some theoretical components. Lastly, I tend to be insecure about myself and my abilities and this experience has given me confidence that everything will be alright.

**Fun anecdote. *The crazy adventure.***

For convenience purposes, at the start of my internship, I decided to buy a foldable bike to be able to bring in the train since I had to bike from my house to Groningen station and from the station in Hoogezand to the institution. One day around 15.30 I was leaving work very tired but biking really fast with the hope of catching an early train. I was so looking forward to arriving home, showering and having some food! However, when I arrived at the station in Hoogezand I saw on the information screen that the next two trains were cancelled due to a disruption in the railways (you can imagine my face when I saw this). So, I called my boyfriend to let him know that I would be later and he decided to check the NS website to see exactly what the problem was. And then he told me that according to the website there would not be any trains until 19.00. WHAT? It was so cold and exactly at that moment it also started to rain. *What am I going to do?*
Well, I couldn't bear the thought of waiting there for more than three hours in the cold and rain for a silly train so a crazy (and this actually might be an easy word) idea crossed my mind:
I decided to bike home.
Yes, after waking up at 5.30 and working for eight hours I decided to bike 20km back with my little foldable bike through the fields with rain and wind against me. Do you know the typical meme "expectations vs reality"? This was totally one of those moments.
I gathered all the good humour that I had left and started my journey with a *kind of* smile on my face. I sent my location to a Whatsapp group of good friends so that they could follow me on the map, and with all the encouragement I received from them I began this crazy journey.
And as I was there in the middle of nowhere, with my waterproof coat completely soaked, no matter how tired or bad-tempered I fell at times (the rain was not helping) I had no choice but to keep going.
And I did it!
It took me one hour and a half, but at last, I arrived home. YES!
No one at my work could believe me the next morning. And suddenly, what broke my proud

moment...one of my colleagues suddenly said “If you would have called back to the house I could have driven you home!”. Bah!

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Appendix 1. Research. Final version in Dutch.

# Het belang van gezichts en gedrags uitdrukkingen van emoties als non-verbale communicatie-indicatoren bij mensen met ernstige verstandelijke beperkingen

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**Abstract**

Dit artikel geeft een uitgebreide bespreking van het belang van gezichts en gedrag manifestaties van emoties als non-verbale indicatoren van de affectieve toestand van mensen met ernstige tot zeer ernstige verstandelijke beperkingen ((Z)EVB). Theorieën en resultaten tot nu toe leiden tot de conclusie dat het uiten van emoties een biologische basis heeft en wordt bepaald door de genetica van onze soort, en daarom universeel is voor de mensheid. De verstandelijk gehandicapte (VB) populatie is daardoor ook in staat om emoties te ervaren en te uiten. Hun expressie, die zich normaal gesproken tijdens de vroege kinderjaren ontwikkelt, kan echter worden beperkt door hun verstandelijke beperking of andere comorbide problemen, en is afhankelijk van de interpretatie die wordt gegeven door zorgverleners en medewerkers in de gezondheidszorg. De evaluatie vereist een goede beoordelingsmethode en bekendheid met het individu. Kortom, een meer gedetailleerd en gepersonaliseerd begrip van de emotionele expressie is essentieel voor een meer nauwkeurige interpretatie van de emoties, behoeften en voorkeuren van deze groep mensen, voor de humanisering van de zorg en voor een verbetering van gepersonaliseerde zorg en zorgplannen.

**Trefwoorden**: ernstige tot zeer ernstige verstandelijke beperking ((Z)EVB), kwaliteit van leven, affect, gezichtsuitdrukkingen, stimuli, universaliteit vs cultuur, gezichtsspieren, gedragsfenotype, non-verbale communicatie, macro- en micro-uitdrukkingen, vertrouwdheid, zelfbeschadigend gedrag , video-opnames, fysiologische waarden, op bewijs gebaseerde manier van werken (evidence-based practice) , zorgplannen, interventies.

**Inhoudsopgave**

**Introductie**

De beoordeling van innerlijke affectieve gemoedstoestanden en mentaal welzijn bij mensen met een ernstige tot zeer ernstige verstandelijke beperking ((Z)EVB) is een gecompliceerde kwestie. De belangrijkste reden is dat ze niet of zeer beperkt in staat zijn om hun gevoelens en gedachten zelf over te brengen vanwege de cognitieve en communicatieve beperkingen die ze ervaren (Vos et al., 2013). Hoewel er enkele methoden zijn om hun psychisch welzijn te meten, zoals gedragsobservaties en fysiologische maatregelen (Walton et al., 2020), vormen innerlijke gemoedstoestanden die ervaren worden door personen met (Z)EVB een minder onderzocht gebied met nog weinig en zeer beperkte gestandaardiseerde methoden. Het is van belang dat hier extra aandacht aan wordt besteed, de voornaamste reden hiervoor ligt in het concept van kwaliteit van leven. Om de kwaliteit van leven van deze groep mensen met een verstandelijke handicap te behouden en verbeteren door de best mogelijke zorg te bieden is het essentieel om hun innerlijke gemoedstoestanden te begrijpen. Met kwaliteit van leven wordt niet alleen verwezen naar objectieve punten zoals ondersteuning van familie en verzorgers en stabiliteit in de routine, maar ook, en nog belangrijker, naar het welzijn van de innerlijke leefsfeer van de persoon en de wijze waarop zij de wereld om zich heen ervaren. Dit innerlijke domein of leefsfeer heeft over het algemeen betrekking op tevredenheid over het leven (het perspectief van het leven dat een persoon heeft) en op affect (bestaande uit stemming en emotie), waarbij het laatste het meest relevante onderdeel is van het subjectieve welzijn van deze populatie vanwege hun beperkte cognitieve capaciteiten (Vos et al., 2013). Maar hoe komt dit affect tot uiting?

Gezichtsuitdrukkingen zijn de belangrijkste non-verbale communicatoren van emotie. Gevolgd door gedragsconsequenties voor die emotie die hand in hand gaan met de emoties die in het gezicht worden uitgedrukt (Walton et al., 2020). Intrinsiek aan onze biologische en genetische aard, is dat emoties worden uitgedrukt vanaf de kindertijd en ze dienen specifieke sociale, cognitieve en fysiologische doeleinden (Adams & Oliver, 2011). Ze hebben een cruciale functie bij reproductie en overleving en, in tegenstelling tot verbale taal, hebben ze een universeel karakter dat binnen onze soort wordt gedeeld, wat betekent dat hun expressie in alle culturen gelijk is (Ekman & Keltner, 1997). Echter, in gevallen waarin ook een (neuro) motorische handicap of beperking aanwezig is, worden deze emoties moeilijker om te “lezen” en nauwkeurig te interpreteren. Personen met een verstandelijke beperking zijn hier zeer kwetsbaar voor en vertonen vaak andere beperkingen, zoals comorbide medische condities, andere psychische stoornissen en/of gedrags- en affectieve problemen. Bovendien kan de symptomatologie van de laatste afwijken van de klassieke vormen van manifestatie, wat het opmerkelijk moeilijk maakt om de emoties te interpreteren (Bernstein et al., 2015).

Het doel van dit artikel is om het concept van het uiten van emoties binnen de ernstig tot zeer ernstige VB populatie te presenteren en de bewustwording van het belang ervan te vergroten voor de verbetering van persoonlijke zorg en een beter begrip van de persoon en zijn omstandigheden. Dit artikel begint met een korte algemene inleiding over de universaliteit van emoties in tegenstelling tot de culturele invloed waaraan emoties van jongs af aan worden onderworpen. Vervolgens wordt de emotionele ontwikkeling en het belang van emoties in de eerste levensjaren uitgelegd. En het sluit af met een bespreking

van de beoordeling van innerlijke en affectieve gemoedstoestanden binnen de ernstig tot zeer ernstige VB populatie.

**Cultuur versus universaliteit van gezichtsuitdrukkingen**

Er zijn verschillende theorieën over de oorsprong van gezichtsuitdrukkingen van emotie. Binnen het theoretische kader van Charles Darwin (1809-1882) en de evolutietheorie, worden gezichtsuitdrukkingen als universeel voor onze soort beschouwd, omdat ze sterk verbonden zijn met de gezichtsspieren (Ekman & Keltner, 1997). Hij stelde voor dat emoties aangeboren zijn in onze biologie en zich aanpassen aan de evolutie, en daarom een functie moeten hebben voor overleving en voortplanting (Adams & Oliver, 2011). Daar was in vroeg onderzoek echter niet genoeg bewijs voor (Matsumoto & Hwang, 2011), dus kozen wetenschappers voor de theorie dat gezichtsuitdrukkingen, als het belangrijkste onderdeel van non-verbale communicatie, op dezelfde manier door cultuur worden bepaald als verbale taal (Ekman & Keltner, 1997).

Latere experimenten uitgevoerd door Tomkins (Matsumoto & Hwang, 2011) suggereerden dat er verschillende gezichtsbewegingen zijn waarbij primaire affecttoestanden betrokken zijn die universeel zijn voor de mensheid, wat de theorie van Darwin ondersteunde en het debat herstelde (Ekman & Keltner, 1997). Deze opvatting stelt dat bepaalde gezichtsuitdrukkingen het resultaat zijn van menselijke motivatie als reactie op stimuli, en daarom kunnen worden gezien als fundamenteel voor groepsharmonie, gezien hun zeer belangrijke leidende rol als non-verbale communicatie van emoties, gevoelens en intenties (Adams & Olivier, 2011).

Er is niettemin een zeer belangrijke culturele invloed op gezichtsgebaren, die in tegenstelling tot gezichtsuitdrukkingen worden gedefinieerd als bewust en opzettelijk, en die per cultuur verschillen. Er zijn bepaalde culturele regels die tijdens de vroege kinderjaren zijn geleerd en die beïnvloeden en bepalen welke stimuli welke reactie oproepen, hetgeen resulteert in dat dezelfde gebeurtenissen verschillende reacties/antwoorden oproepen in verschillende culturen (bijv. bij begrafenissen) (Ekman & Keltner, 1997). Dit betekent dat een specifieke emotie kan worden veroorzaakt door verschillende stimuli in verschillende culturen, maar de manier waarop de emotie zelf in het gezicht en in het gedrag wordt uitgedrukt, blijft gelijk (Matsumoto & Hwang, 2011). Daarom is er een breed geaccepteerde basisset van emoties. Deze set bevat emoties zoals geluk, angst, woede, verdriet, verrassing en walging (Adams & Oliver, 2011) en verbindt deze met dezelfde componenten van de gezichtsspieren.

Het perspectief van universaliteit is een stap verder gegaan, in de lijn van de evolutietheorie (Darwin, 1872), bij het onderzoeken van de genetische impact op gezichtsuitdrukkingen van emotie. Uitkomsten daarvan tonen aan dat bijvoorbeeld mensen met aangeboren blindheid (blind sinds de geboorte) dezelfde uitdrukkingen produceren als ziende mensen en dat de verschillen in emotionele uitdrukking minder zijn in vergelijking met naaste familieleden van deze personen (Matsumoto & Hwang, 2011). Er is ook verondersteld dat de expressie van innerlijke gemoedstoestanden verschilt bij personen met enige vorm van genetische afwijking die direct een verstandelijke beperking veroorzaakt. Dit leidt tot de theorie van het "gedragsfenotype", die stelt dat de genetische afwijking het vooruitzicht op bepaald

gedrag beïnvloedt (Adams & Oliver, 2011). Dit argument zal duidelijker worden in het laatste deel van dit artikel, waar specifieke syndromen die verstandelijke beperkingen veroorzaken en hun specifieke gedragsfenotypes worden besproken.

**Emotionele ontwikkeling en micro-expressies van emoties**

Gelaatsuitdrukkingen die emoties weergeven, worden in de vroege kinderjaren ontwikkeld, waardoor non-verbale communicatie tussen het kind en de verzorger mogelijk is vóór de verbale taalontwikkeling. De vroegst geïdentificeerde uitdrukkingen worden geassocieerd met smaak, zowel smaak als walging, en ongedifferentieerde angst. De complexiteit van gezichtsuitdrukkingen neemt gedurende de eerste twee levensjaren toe en worden gevormd in relatie met de sociale context van het kind met zeer specifieke resultaten. Dit continue proces valt samen met andere cognitieve processen. Voorbeelden zijn het identificeren van de intentie van anderen, het zelfbeeld, de regulatie van emotie en de ontwikkeling van een "innerlijke affectieve kaart", die erg belangrijk zijn voor het labelen van ervaren emoties door jezelf en door anderen en een cruciale rol spelen in sociaal gedrag (Adams & Oliver, 2011).

Zeer ernstig verstandelijk gehandicapte mensen missen vaak verbale communicatieve vaardigheden en zijn beperkt tot elementaire non-verbale manieren van uitdrukking om de buitenwereld bewust te maken van hun affectieve toestand. Er is discussie ontstaan over de vraag of diep verstandelijk gehandicapte mensen hetzelfde scala aan basisemoties kunnen ervaren als de algemene bevolking. Dit debat kent vele dimensies die rekening houden met de oorsprong en het niveau van de handicap, alsmede met de mogelijke beperking in het ervaren van emoties en/of in hun expressie.

Terwijl gezichtsgebaren, zoals in de vorige paragraaf besproken, opzettelijk zijn en worden gevormd door culturele en sociale achtergronden en zelfs persoonlijkheid, zijn gezichtsuitdrukkingen spontaan en onwillekeurig. Er zijn twee soorten gezichtsuitdrukkingen te onderscheiden: macro-expressies en micro-expressies. Het optreden van eenvoudige emoties zonder verberging die 0,5-4 seconden duren en alle gezichtsspieren laten functioneren, staan bekend als macro-expressies en vinden plaats wanneer we ons veilig voelen. Micro-expressies daarentegen duren een fractie van een seconde en zijn bijna niet waarneembaar voor het blote oog. Ze zijn een teken van verborgen emoties of zeer snel verwerkte onverholen emotionele toestanden en kunnen niet vrijwillig worden gecontroleerd. Ze worden bestuurd door twee neurale paden, respectievelijk het piramidale kanaal en het extrapiramidale kanaal. Wanneer wordt geprobeerd de ervaren emoties te beheersen, worden beide systemen geactiveerd en ontstaat er een strijd tussen de gezichtsspieren, wat resulteert in het uiten van micro-expressies. Het bestaan van de laatste werd geverifieerd door het analyseren van films van psychotherapiesessies in "slow motion" (Matsumoto & Hwang, 2011). Het bestaan van zulke snelle uitingen van emoties biedt een mogelijke verklaring waarom het zo ingewikkeld kan zijn om bepaalde uitingen bij (Z)EVB mensen op te merken, tot het punt dat men zou kunnen veronderstellen dat ze niet in staat zijn om emoties te ervaren en te uiten.

**Ernstige tot zeer ernstige verstandelijke handicaps; beoordeling van de innerlijke gemoedstoestand**

Als antwoord op de vraag of (Z)EVB mensen emoties ervaren en zich kunnen uiten door middel van lichaamstaal, is op basis van gedragsstudies waargenomen dat personen met ernstige tot zeer ernstige verstandelijke beperkingen een groot scala aan emoties ervaren en evenzeer als de algemene bevolking in staat zijn om deze uit te drukken door middel van gezichtsuitdrukkingen en gedrag (Adams & Oliver, 2011). Deze emoties zijn echter minder of geenszins cultureel beïnvloed en hebben een meer spontaan en ongecontroleerd karakter dan bij de rest van de bevolking.

Bovendien vertonen ernstig tot zeer ernstige verstandelijk gehandicapten vaak al op vrij jonge leeftijd tekorten in het uiten van emoties. Er is zeer weinig literatuur op dit gebied, zowel met betrekking tot de chronologische als de mentale leeftijd van deze groep van personen vanwege de onmogelijkheid tot zelfevaluatie en de verminderde verbale/non-verbale communicatie. In wezen hebben ze geen expliciete manier om onze aannames te corrigeren en hun communicatie met de buitenwereld is daarom sterk afhankelijk van de verzorger die de kleine non-verbale indicatoren, zoals gezichtsuitdrukkingen, interpreteert. Het is empirisch bewezen dat zorgverleners die bekend zijn met de gehandicapte persoon beter en nauwkeuriger zijn in het herkennen van gezichtsuitdrukkingen van de persoon dan onbekende mensen, deels omdat ze minder geneigd zijn subtiele uitdrukkingen over het hoofd te zien. Het vereist echter zeker ervaring en een nauwgezette observatie voor een preciezere interpretatie (Adams & Oliver, 2011).

Vanwege hun verminderde vermogen om verbaal te communiceren, is het belangrijk om te begrijpen hoe gedrag zich verhoudt tot het uiten van emoties en de diversiteit op verschillende niveaus, alsmede de etiologie van een verstandelijke beperking. Zelfbeschadigend gedrag gaat bijvoorbeeld meestal gepaard met de ervaring van negatief affect, zoals pijn, angst of ongemak. In een veel lager percentage kan het ook het gevolg zijn van spontane, ongecontroleerde bewegingen (Adams & Oliver, 2011).

Sommige genetische aandoeningen die leiden tot ernstige dan wel zeer ernstige verstandelijke beperkingen, bijvoorbeeld het Fragiele X-syndroom en sommige gevallen van het Downsyndroom, geven extremen weer van bepaalde innerlijke gemoedstoestanden, zoals respectievelijk sociale en interne angst en depressie (Adams & Oliver, 2011). Dit komt door affectieve eigenschappen in onze genen die ons ontvankelijker maken voor bepaalde emotionele reacties (Vos et al., 2013). Een interesse voor sociaal contact is herhaaldelijk waargenomen bij individuen met het fragiele X-syndroom, maar deze interesse gaat meestal gepaard met vermijdingsgedrag, toename van de activiteit van de zweetklieren, zelfbeschadigend gedrag en verminderd oogcontact, als gevolg van de genoemde angst en ongemak. Er zijn andere genetische aandoeningen die ook van invloed zijn op sociaal gedrag, zoals het syndroom van William, dat verhoogde sociale interesse, abnormaal kijkgedrag en abnormale vriendelijkheid vertoont, ook met vreemden. Of het Angelman-syndroom, gekenmerkt door hyperactiviteit en verhoogde mate van vriendelijkheid, lachen en glimlachen (Adams & Oliver, 2011). Het is daarom van belang om rekening te houden met de etiologie van de handicap en de specifieke persoon bij het interpreteren van affectieve gemoedstoestanden voor een meer nauwkeurige lezing.

Er zijn een paar benaderingen die worden gebruikt om de affectieve toestand van een persoon met (Z)EVB te beoordelen en te evalueren. Een van hen en de meest toegepaste is gebaseerd op observatie door zorgverleners of medewerkers in de gezondheidszorg die verantwoordelijk zijn voor de zorg van het persoon. Dit bestaat meestal uit het bekijken van video-opnames van de gehandicapte om te proberen nieuwe dingen te zien, zoals bewegingen, gezichtsuitdrukkingen en lichaamstaal die voorheen niet waarneembaar waren (Adams & Oliver, 2011). Gedragsobservaties zijn belangrijk omdat ze unieke kennis kunnen verschaffen over de innerlijke gemoedstoestand van een persoon door stemming en emotie te vergelijken. Opnames van personen kunnen worden vastgelegd tijdens dagelijkse routinematige activiteiten zoals verzorgingsmomenten (haar borstelen, massage…) of eet-situaties (Vos et al., 2013). Deze opnames kunnen vervolgens door de zorgverleners worden bekeken, hetgeen helpt om een goed beeld te krijgen van de algemene emoties die de persoon lijkt te ervaren tijdens de specifieke activiteiten. Er zijn verschillende methoden die deze benadering hanteren, bijvoorbeeld de Petry & Maes-methode, die elk waargenomen gedrag op een schaal van 5 punten beoordeelt, van zeer negatief affect tot zeer positief affect (Vos et al., 2013). Het is echter belangrijk om in gedachten te houden dat wij als mensen nogal geneigd zijn om wat we zien in onze eigen termen te interpreteren, en het is daarom cruciaal om binnen een professioneel geleide groep te werken en ideeën uit te wisselen, elkaars perceptie aan te vullen en te praten over wat het beste lijkt te zijn voor de persoon in kwestie.

Naast de benadering door observatie is er een meer recente benadering die zich richt op het meten van fysiologische waarden. Dit is echter een meer algemene methode, en niet realistisch voor de dagelijkse praktijk, die gericht is op de emotionele fysiologische verschijnselen zelf en nog moet worden aangevuld met een meer gedetailleerde kennis van de gedragsobservatie van het individu (Walton et al., 2020). Een andere benadering is bijvoorbeeld de *Interact Short Form- People with Profound Disabilities-editie* (Liu et al., 2007). Dit is een observatie-instrument met elf items, waarvan het doel is om de innerlijke gemoedstoestand van mensen met een ernstige verstandelijke beperking te helpen beoordelen, zowel vóór als ná interventies of relevante veranderingen.

Verder gaat het niet om gezichtsuitdrukkingen alleen, maar ook om het “lezen” van de hele gedragsverandering als reactie op een prikkel, aangezien het hele gedrag betrekking heeft op de uiting van affect en op het ervaren van pijn. Voor dit laatste zijn verschillende methoden onderzocht om pijn te beoordelen wanneer er sprake is van een gebrek aan of een beperking van expressieve en verbale taal. Een van deze methoden is de *Pain and Discomfort Scale* (PADS), ontwikkeld door Bodfish, Harper, Deacon en Symons (2001), welke is gebaseerd op gezichtsuitdrukkingen en houding of beweging. Hoewel het een vrij moeilijk hulpmiddel is om te gebruiken, geeft het wel een betrouwbaarder beeld van de mate van ervaren pijn. Sommige deskundigen stellen een combinatie van deze methode voor met bekendheid, flexibiliteit en een globaal begrip van de omstandigheden van de persoon voor een hogere nauwkeurigheid en suggereren dat dit de beste klinische beoordeling van pijn is die we momenteel hebben (Adams & Oliver, 2011).

Elk van deze methoden vereist aandacht en motivatie om als sociale stem voor deze groep van gehandicapte mensen te dienen en om hun voorkeuren, behoeften en wensen te kunnen vervullen (Walton et al., 2020).

## Conclusies

Welbeschouwd zijn er verschillende conclusies te trekken uit de besproken informatie. Ten eerste kan worden geconcludeerd dat, gezien de evolutionaire en genetische aard van het uiten van emoties, mensen met (Z)EVB ook basisemoties ervaren en vertonen, die registreerbaar zijn voor oplettende en gemotiveerde waarnemers en nuttige informatie kunnen verschaffen om de persoon en zijn omstandigheden en innerlijke gemoedstoestanden beter te begrijpen en daardoor de zorg te vermenselijken.

Ten tweede kunnen bevindingen op het gebied van emotionele ontwikkeling en (micro)expressies van emoties in relatie tot ernstige of zeer ernstige handicaps uitermate nuttig zijn om de situatie van de patiënt beter te begrijpen, alsmede de humane interactie en sympathie met hem of haar te versterken. Het kan ook dienen om de nauwkeurigheid van de diagnose te verhogen door een completer beeld te krijgen en door betere en meer geschikte gepersonaliseerde zorgplannen en doelen te ontwikkelen.

Ten derde is door observatiestudies getest dat personen met ernstige tot zeer ernstige verstandelijke beperkingen wél emoties ervaren, maar dat de manifestatie daarvan kan verschillen van de uitdrukkingwijze bij de rest van de bevolking vanwege de mate van handicap. Bovendien is het erg belangrijk om gezichtsuitdrukkingen van emoties te observeren en te begrijpen, omdat het mogelijk direct inzicht kan geven in de innerlijke affectieve gemoedstoestanden van die personen die hun emoties niet verbaal kunnen uiten. Deze observatie vereist echter een goede meetmethode en nauwgezette aandacht, aangezien de uiting van emoties die door deze kwetsbare groep worden gepresenteerd subtieler, spontaner en enigszins anders kan zijn in vergelijking met die waargenomen in de rest van de bevolking en om deze reden vaak over het hoofd wordt gezien en onopgemerkt gelaten.

Tenslotte is het van vitaal belang om dit thema verder te onderzoeken en om met nieuwe en meer nauwkeurige methoden en instrumenten de innerlijke affectieve gemoedstoestanden, het mentale welzijn en de kwaliteit van leven van de ernstige tot zeer ernstige verstandelijk gehandicapte medemensen te beoordelen. Het zal ook helpen de kwaliteit van *evidence-based practice* te verbeteren en betere en meer gepersonaliseerde zorg interventies en -programma's te ontwikkelen.

## Dankbetuigingen

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Appendix 2. Care plan.

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S3564371
Opdracht: Begrijp wat een zorgplan is en ontwikkel een model op basis van een case study

EEN (VERPLEEG)ZORGPLAN

**Wat zijn zorgplannen?**
Zorgplannen zijn schriftelijke documenten die dienen om informatie over de zorg van een persoon te organiseren. Ze omvatten strategieën om de persoon te helpen zijn volledige therapeutische potentieel te bereiken en maximaal dagelijks welzijn te ervaren. [1]

**Wat is de focus van een zorgplan?**
De focus van een zorgplan ligt niet op de diagnose van een persoon, maar juist op wat voor hem/haar in het dagelijks leven belangrijk is. Hoe is het mogelijk om goede dagelijkse zorg te verlenen en te coördineren en de ondersteuning te bieden die de persoon nodig heeft binnen de complexiteit van zijn behoeften. In het kader van een verstandelijke beperking is het bieden van veiligheid en continuïteit en kwaliteit van zorg van groot belang.[1]

**Waarom is een zorgplan belangrijk?**
Een zorgplan identificeert duidelijk de persoon die de zorg ontvangt en de mensen die betrokken zijn bij het verlenen van deze zorg, en fungeert als communicatiemiddel tussen de zorgverleners, andere medische professionals, families, etc. Ze worden gebruikt tijdens vergaderingen om de status van de persoon te evalueren en tijdens de dagelijkse rapporten als referentiepunt van hoe goed de persoon de dag doorbracht.[1]

**Wat staat er in het (verpleegkundige) zorgplan?** [2]
-Gezondheidsbeoordeling, relevante medische resultaten en diagnostische rapporten.
-De rol van het dagelijkse zorgpersoneel.
-Interventies die direct op de cliënt zijn afgestemd door de verpleegkundigen of andere zorgprofessionals die verantwoordelijk zijn voor de persoon.
-Definieer de doelen van de persoon in kwestie om deze op te nemen in het behandelplan en om beslissingen te nemen. Wanneer de cliënt zelf geen doelen kan bepalen (zoals op afdelingen met een ernstige verstandelijke beperking), kunnen specifieke doelen worden bepaald ten behoeve van de zorg en het welzijn van de persoon (gerelateerd aan interventies).
-Welke acties moet het personeel ondernemen, instructies voor bepaalde interventies.
-Rechtvaardiging voor interventies om te voldoen aan de empirisch onderbouwde vereisten.

Evaluatie/rapportage: worden gebruikt om de uitkomst van de verpleegkundige interventies/zorgplan te documenteren.

Beroepssituatie: Dit is een geval van een jongen met een ernstige mentale handicap, maar als een verschil met de groep waarmee ik stage loop, hoewel hij beperkingen heeft, is hij in staat om naar “school” te gaan en te communiceren met leden van het personeel en zijn familie.

Bron: https://www.nccd.edu.au/case-studies/william-extensive-cognitive

## William's story

William is a 16-year-old boy with a diagnosis of severe intellectual disability and autism spectrum disorder. He attends a specialist school in a large regional city and participates in some mainstream programs as part of the school's satellite unit situated in a secondary college campus near his school.

William is non-verbal, communicating his needs using gestures, some keyword signing, and the Picture Exchange Communication System (PECS). Though William generally enjoys attending school, he has difficulties with sensory integration and requires significant supervision and assistance at all times and in all settings.

William requires extensive support to manage his behavioural responses to sensory stimuli. It is difficult to predict his reaction to any given sensory input. As a result, staff regularly undertake functional behaviour analyses to evaluate William's engagement with his environment in all settings – school sites, the community and the home. From these analyses, a comprehensive behaviour management plan is put in place to ensure William is provided with consistent responses and strategies that best support his complex needs.

William's educational program focuses on functional skills in the key areas of self-care, communication, personal safety and preparing for post-school options. William requires intensive adult assistance for all components of his educational program.

Current personalised learning plan goals for William include:

- independently completing some steps when dressing and undressing
- indicating personal needs associated with being hot, cold, hungry, or thirsty by using gesture, sign or PECS
- indicating feelings such as 'happy', 'sad', 'angry', 'worried', 'scared' or 'confused' by using gesture, sign or PECS
- communicating likes and dislikes through gesture, keyword sign or PECS
- completing some steps associated with preparing his own meals
- with prompting, following visual steps in basic hygiene procedures
- finger-feeding independently and attempting to use utensils when eating
- responding to single word safety instructions from a familiar adult, such as 'stop', 'wait' and 'come'
- recognising and communicating when feeling unsafe
- recognising warning signs in the environment.

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*(vertaling:)*
*William is een 16-jarige jongen met een diagnose van een ernstige verstandelijke beperking en een autismespectrumstoornis. Hij gaat naar een gespecialiseerde school in een grote regionale stad en neemt deel aan een aantal reguliere programma's als onderdeel van de satelliet eenheid van de school op een middelbare universiteitscampus in de buurt van zijn school.*
*William communiceert non-verbaal zijn behoeften met behulp van gebaren, het ondertekenen van trefwoorden en het Picture Exchange Communication System (PECS). Hoewel William over het algemeen graag naar school gaat, heeft hij problemen met zintuiglijke integratie en heeft hij te allen tijde en in alle situaties veel toezicht en hulp nodig.*
*William's educatieve programma is gericht op functionele vaardigheden op de belangrijkste gebieden van zelfzorg, communicatie, persoonlijke veiligheid en voorbereiding op opties na school. William heeft intensieve hulp van volwassenen nodig voor alle onderdelen van zijn onderwijsprogramma.*

*De **huidige persoonlijke leerplandoelen voor William zijn** onder meer:*
*-Het zelfstandig uitvoeren van enkele stappen bij het aan- en uitkleden.*
*-Het aangeven van persoonlijke behoeften in verband met warm, koud, hongerig of dorstig zijn door middel van gebaren of PECS.*

*-Het aangeven van gevoelens zoals blij, verdrietig, boos, bezorgd, bang of verward door middel van gebaren of PECS.*
*-Communiceren van voorkeuren en antipathieën door middel van gebaren of PECS.*
*-Het voltooien van enkele stappen die verband houden met het bereiden van zijn eigen maaltijden.*
*- Zelfstandig vingervoeden en gebruiksvoorwerpen proberen te gebruiken tijdens het eten.*
*-Reageren op veiligheidsinstructies in één woord van een bekende volwassene, zoals stoppen, wachten en komen.*
*- Herkennen en communiceren bij onveilig gevoel.*
*- Het herkennen van waarschuwingssignalen in de omgeving.*

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Op basis van deze leerdoelen (mogelijk gesteld door bijvoorbeeld de orthopedagoog) **heb ik een zorgplan ontwikkeld** dat aansluit bij de complexe behoeften van William en hem langzaam zou helpen om zijn volledige potentieel te bereiken.

| | |
|---|---|
| **BEOORDELING** | -Ernstige verstandelijke beperking gecombineerd met een autismespectrumstoornis.<br>- Non-verbale communicatie met gebaren en afbeeldingen.<br>-Heeft constante begeleiding nodig voor het uitvoeren van eenvoudige taken en voor controle en begrip van gedragsreacties. |
| **VERPLEEGKUNDIGE/ ZORG DIAGNOSE** | Moeilijkheden met sensorische integratie. Gedragsreacties op zintuiglijke prikkels zijn onvoorspelbaar en komen niet noodzakelijk overeen met een normale reactie op de aangeboden prikkels. |
| **DOELEN** (Wat hij zou kunnen doen) | 1)Hij moet gestimuleerd worden om taken uit te voeren die hij zelf kan: zichzelf aan-/uitkleden.<br>2)Communiceer actief basisgevoelens zoals boos/verdrietig/bang/gelukkig/moe/verward en wel/niet leuk vinden door de non-verbale communicatiemiddelen die hij heeft (gebaren, afbeeldingen...)<br>3) Bereid zijn eigen maaltijden (breng ze naar zijn bord) en eet alleen, indien mogelijk, met behulp van een vork/lepel.<br>4) Correct/dienovereenkomstig reageren wanneer medewerkers hem vragen te stoppen, wachten, komen... |
| **INTERVENTIES** (Wat het personeel zou moeten doen) | 1) Geef William structuur en begeleiding door hem te helpen de volgende stappen van een routine te leren kennen, zoals aan-/uitkleden, baden, eten<br><br>door zowel eenvoudige verbale als non-verbale communicatie: vb. hem een eetbord laten zien, hem zijn t-shirt, een zwem kraag/douchekop, etc. overhandigen. Niet doorgaan naar de volgende stap voordat de vorige met succes is voltooid. Om hem te helpen de stappen te integreren die nodig zijn om een actie uit te voeren en door te gaan naar de volgende.<br>2) Vraag William hoe hij zich voelt als hij onvoldoende reageert op bepaalde prikkels. Hij moet reageren met gebaren / wijzen op bepaalde tekeningen van verschillende gezichtsuitdrukkingen (verhogende en alternatieve communicatiesystemen). Dit zal hem hopelijk helpen om beter zijn reactie te realiseren en of het nodig of adequaat is. (BEELDEN→ pictogrammen/echte specifieke afbeeldingen van William zelf als |

| | |
|---|---|
| | pictogrammen niet werken)<br>4)Geef duidelijke en niet gecompliceerde zowel verbale als non-verbale instructies voor acties zoals stoppen, wachten, komen... en rapporteren van de reactie van William. |
| **RATIONALE** | 1)Door zijn autisme stoornis heeft William constant begeleiding nodig bij dagelijkse taken. Het zal hem helpen wat structuur te krijgen om hem de volgende stappen van een routine te laten weten. Doe dit rustig, zonder haast naar de volgende taken om hem de tijd te geven om bepaalde acties zelf uit te voeren wanneer hij kan.<br>2) Hij heeft gedragsproblemen die ook verband houden met het niet begrijpen van zijn eigen emoties en hun context. Door de tijd te nemen om deze emoties samen te analyseren, zal William bepaalde emoties beter kunnen associëren met bepaalde stimuli. Hij zal dan hopelijk ook leren om zelf te communiceren wat hij voelt of wat hij nodig heeft.<br>3) Zelf eten bereiden en zelf eten is onderdeel van het doel om zijn zelfstandigheid te vergroten. Het is belangrijk dat hij met deze kleine taken, hoewel altijd onder toezicht, leert hoe hij voor zichzelf moet zorgen en dat hij sommige dingen zelf kan doen.<br>4) Door zijn autisme stoornis zal hij waarschijnlijk op sommige punten ongeduld tonen. Het is belangrijk dat hij leert te doen wat hem wordt opgedragen om enige flexibiliteit in zijn dagelijkse routine te behouden. |
| **EVALUATIE/ RAPPORTAGE** | *Uitgevonden voorbeeld:*<br>18/September/21<br>William helpt rustig bij het uitkleden en blijft rustig tijdens het wassen. Hij kan zijn dagkleding bijna volledig zonder hulp aantrekken.<br>Hij bleef de hele ochtend in een prachtige kalme staat. Hielp met het bereiden van zijn eten door het broodbeleg te kiezen en kon eten met behulp van een plastic vork.<br>Toen hem werd gevraagd om mee te doen voor de theetijd, begon hij plotseling te schreeuwen en toen te huilen. Vervolgens werd hem duidelijk gevraagd "wat er aan de hand is" en kreeg hij enkele foto's te zien zodat hij er een kon kiezen. Na verschillende pogingen koos hij er uiteindelijk een uit die naar het toilet uit beelde, dus hij werd geholpen om daarheen te lopen.<br><br>Daarna bleef hij een beetje nerveus tot de nacht, haastte zich naar de volgende taken, maar hij luisterde wel toen hem werd gevraagd te wachten. Er waren geen verdere incidenten. |

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[2]https://nurseslabs.com/nursing-care-plans/#types_of_nursing_care_plans

[3]https://www.nccd.edu.au/case-studies/william-extensive-cognitive

Appendix 3. Ontdekkend Kijken description with pictures and links.

I had the chance to participate in two of these observational method sessions. The sessions were based on the methodology of Ontdekkend Kijken (Discovery Awareness), which was developed in the Netherlands and attempts to improve the treatment of people with disabilities and behavioural problems by means of video analysis. More information can be found in the following links:
http://eprints.nottingham.ac.uk/43360/
https://www.heijkoop-academy.nu/wetenschappelijk-onderzoek-ontdekkend-kijken-discovery-awareness/